

Executive Summary Report

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THE MISSOURI PLANNING COUNCIL FOR DEVELOPMENTAL DISABILITIES

Statewide Needs Assessment



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PREFACE

The Missouri Planning Council for Developmental Disabilities (MPC) is a federally-funded, 23-member consumer-driven council appointed by the Governor. Public Law 106-402 mandates that the Council is to plan, advocate for, and give advice as to programs and services for persons with developmental disabilities. The focus of such programs is mandated to increase opportunities for self-determination, independence, productivity, and integration into communities. The Council's mission is to support communities to include all persons with developmental disabilities in every aspect of life.

The Council is required by the United States Department of Health and Human Services, Administration on Developmental Disabilities to develop a five-year plan to guide its efforts in meeting the federal mandate. This plan must be based on data-driven strategic planning for advocacy, capacity building, and systems change related to the federal areas of emphasis: Employment, education, housing, transportation, health, childcare, quality assurance, formal and informal community supports, and recreation. Before completing the five year plan, the Council embarked upon a process to assess the extent to which services, supports, and other assistance are available or unavailable to individuals with developmental disabilities and their families. The comprehensive statewide needs assessment also assisted the Council in determining the extent to which individuals and families have the ability to access and use services provided in their community; participate in opportunities, activities, and events offered in the community; and to contribute to community life.

In order to carry out this multiyear task, the Council provided partial support to eleven Regional Advisory Councils and contracted with other developmental disabilities organizations in hosting 127 focus groups involving 975 participants. The focus groups were conducted in 110 of Missouri's 114 counties. Written surveys were also conducted involving 737 individuals. Both individuals with developmental disabilities and their families were represented in the focus group and survey participants. In addition, participants were selected to allow diversity in their geographic locations, the type of disability that they or their family member experience, the age of the individual with a disability, and whether or not the individual received services from the state service system.

The Council wishes to express its gratitude for the assistance of the Institute on Human Development, University of Missouri Kansas City; Regional Advisory Councils; and other entities and organizations, committed to serving Missourians with developmental disabilities in completing this needs assessment.

The five year plan developed from this assessment may be accessed at the Missouri Planning Council's web site: www.mpcdd.com or by calling 800-500-7878.

EXECUTIVE SUMMARY

In the years 2004/2005, the Missouri Planning Council for Developmental Disabilities, with assistance from Regional Advisory Councils, conducted a statewide needs assessment. Individuals with disabilities and family members in each of the 11 MRDD Regions in Missouri completed a written survey. The majority of the 737 respondents were family members (63.5%).

Over two thirds of those responding had received services (68.9%). A total of 127 focus groups were held in 110 of Missouri's 114 counties. There were 975 individuals who participated in the focus groups, 41% (400) were individuals with a developmental disability, and the other 59% (575) were family members. Slightly over two thirds (64%) of the focus group participants received services. The following summarizes the results of both the written surveys and the focus groups.

Employment Issues:

People with disabilities were reported to most likely work in sheltered employment (42.2%) or non-employment situations (37.3%), and reported least likely in regular jobs in the community (66.7%). Over 50% rated options related to regular jobs in the community as inadequate (51.8%). Community employment options with paid support were also seen as inadequate by 40.2% of the respondents and only fair by 27.9%. Respondents split on how they perceived the adequacy of sheltered employment. A little over 45% saw sheltered employment as inadequate (21.1%) or fair (24.4%), while 55% saw it as good (34.6%) or excellent (19.9%). About 71% reported that opportunities for regular or supported employment were either inadequate (42.4%) or fair (29%). Focus group respondents identified *few or no job opportunities, and employer perceptions, attitudes and lack of understanding*, as the top two employment challenges. Some other challenges identified included, *lack of transportation, lack of employer supports, concern with capacity of employment provider, and a mismatch with the person's vocational interests or abilities/skills*. By far, the number one employment help and support identified by focus group members was *sheltered employment*. Some other employment helps/supports reported being received included, *employment supports through public/private county and local organizations and providers, regular jobs obtained through typical supports, and community employment with paid supports*.

Residential Setting Issues:

The most typical residential setting was reported to be at home with family or friends (57.4%). A place of their own was seen as not available (26%) or only somewhat available (54.8%). At home with family or friends was seen as the most available source (79%). Community based housing/living opportunities was reported by the majority of respondents as inadequate (39.2%), or fair (32.3%). The number one housing issue identified by focus group respondents was the, *lack of accessible, affordable, safe housing in the community*. Several other problems identified included, *need for more in-home supports and services, long waiting lists for HUD housing and other community programs, challenges of living on one's own in the community, and the impact of community and housing industry perceptions about persons with DD on availability of housing*. The two housing supports respondents cited the most were, *living with family, and support from, public programs, resources, and organizations that help with housing (e.g., HUD programs)*. Other housing supports identified included, *persons living in their own home in the community with generic or paid supports, and community organizations, neighbors, businesses, banks, etc. that have provided housing supports*.

Transportation Issues:

The transportation that people with disabilities were most likely to use was public transportation (47.1%). Special transportation (38.6%) and Self-transportation (37.1%) were respectively seen as the least likely transportation choice. Special transportation was reported as the most inadequate option (49.7%). Self transportation was the option most often rated as excellent by respondents (36.1%). When asked to rate the opportunities for community-based transportation for people with disabilities, 72% of the respondents rated it as *fair* (29.8%), or *inadequate* (42.6%). Without question, the most prominent transportation issue sited by focus group respondents was the *lack of availability of transportation, especially in rural areas*. Other problems identified pertained to, *cost to meet transportation needs, limited transportation schedules, reliable consistent transportation services (e.g., arrive on time) and vehicle accessibility*. Overall, transportation support received through *various public transportation providers or collaborations*, was discussed most frequently by focus group respondents. Other transportation supports identified included, *transportation resources offered through community agencies and organizations, family provision of transportation supports, volunteers to assist with transportation, and specialized transportation services for persons with disabilities*. When asked to rate the opportunities for community-based transportation for people with disabilities, respondents rated this as *inadequate* (42.2%).

Child Care Issues:

Child care was rated as most likely to be provided by family or friends (69.6%). The least likely by regular childcare providers (49%). Family child care received the highest rating of adequacy (68.7%). Segregated child care and regular childcare received the lowest (52.9% and 40.9% respectively). Opportunities for community based childcare for children with disabilities was rated as inadequate by 57.4% of the respondents, and fair by 16.1%. Focus group members stated that the most challenging child care issue was that there are *few or no options for childcare* in their communities. Some other child care problems revolved around *a lack of providers or sitters with specialized skills to support kids with a disability, systems requirements that may limit childcare services, lack of family/friends to provide childcare and excessive costs for childcare*. Focus group participants reported that they have received the most child care support from *family or friends who assist with arranging or providing childcare services*. Some other child care help came from *inclusive childcare providers, and communities providing funding resources to develop and expand childcare options*, as well as *respite supports*.

Early Intervention Service Issues:

The most common early intervention service utilized was First Steps (41.8%), the least were those through regular pre-schools. Over 61% of those responding rated the First Steps program as good (34.4%) or excellent (26.7%), and over 58% rated the Head Start program as good (38.5%) or excellent (20.3%). Special needs pre-school was rated lowest (34.1% inadequate, 20.7% fair). Therapies were reported as fair or good by almost 59% of those responding. Over 73% reported that early intervention services were either mostly available (30.3%), or only somewhat available (43.2%) in their community. By far, Focus group respondents reported that they had received early intervention supports through the *First Steps program and other infant/toddler programs, and other community resources (e.g. churches, civic organizations) supporting early intervention services*. Other comments included that the *Parents as Teachers program offered supports for the child and family, and Head Start assisted in preparing child for school*.

Educational Service Issues:

The most utilized educational type was Special public school education (46.1%), followed by students who are included in regular public school education (33.7%). The least likely to be utilized was private/home education. The highest rated educational type was special public school education (good (37.6%, excellent 15.8%). Private/home education was seen as the most inadequate (34.8%) followed by state schools (29.7%). Inclusive educational opportunities were rated as not available (17.1%) or somewhat available (49.2%). Transition services were rated as not available (22.6%) or somewhat available (48.4%). Post-high school opportunities were rated as not available (37.4%) or somewhat available (40.5%). Focus group respondents overwhelmingly reported that a *lack of quality; individualized supports are minimizing student potential*. Additional challenges sited were a *lack of school knowledge of best practices supports for students with developmental disabilities, school personnel misperceptions/attitudes concerning learning capacity and support needs of students with developmental disabilities, and lack of resources limiting needed supports and services*. The majority of focus group members expressed that *students/families were satisfied with school services received*. Other examples of educational support sited include, *teachers and classroom aides supported the student to be successful, supports received from other agencies that assisted students, families, and school systems, and early childhood programs facilitated child's readiness for school*.

Health Care Service Issues:

Respondents were most likely to use a doctor's office for health care services (62.2%). Least likely locations to be used were residential health care centers (3.6%) and local health departments (3.6%). With the exception of residential health care centers, all other health care services were rated as inadequate or fair by over 50% of those who responded. Hospitals/emergency rooms were rated by almost 70% of the respondents as inadequate (30.0%), or fair (39.9%). Doctor's offices were rated as inadequate (20.5%), or fair (46.7%) by over 67% of the respondents. Interestingly, the health care services least used were the ones that received the highest adequacy rating. (Community health clinics, 32.3%; Residential health care centers, 45%; and Local health departments, 28.5%). When asked about the availability of health care and dental services for people with disabilities, 39.9% indicated health care services in the community as *not available*, and 50% reported dental care as *not available*. Focus group respondents sited *public health insurance program (e.g., Medicaid) issues that impact persons with developmental disabilities* most often as a pressing health care challenge. Other problems identified were, *a lack of dental services in proximity to the community, lack of general medical resources close to the community, and lack of affordable private insurance and increasing coverage*. Health care supports were received from *doctors and other medical professionals*. Another major support sited reflects that there is, *no problem finding medical and/or dental care*. Other supports received include, *Developmental Disability service agencies that assist with obtaining health services; family, friends, church members, etc. that help get them to medical/dental care, and health care paid through Medicaid/Medicare*.

Recreation/Social Opportunity Issues:

The most likely recreation opportunities in the community were special/segregated recreation and social activities/events (49.8%). Regular community sponsored activities followed at 34.1%. Regular community sponsored recreation and accessible community sponsored recreation were rated as inadequate or fair by almost 72% of the respondents.

Special/segregated recreation/social opportunities only fared slightly better with almost 60% rating them as inadequate or fair as well. Availability of accessible recreation opportunities were reported as not available by 28.7%, and somewhat available by 43.3%. Availability of social opportunities in the community were rated as not available by 27.2%, and as somewhat available by 48.2%. Focus group respondents sited *no recreation opportunities available* most often as a recreation/social challenge. Other problems identified include, *limited availability of accessible community-based social and recreation activities, community perceptions, attitudes about persons with developmental disabilities that limit recreational opportunities, transportation issues (e.g., (costs, schedules, availability), and the need for more affordable recreation activities/events.* The majority of respondents shared that had received supports from *communities and organizations that would provide accessible recreation options and support.* Other help received came from *segregated programs that provide recreation programs/activities, and community initiatives that increase community recreation options for persons with developmental disabilities.*

Community Resource/Support Issues:

The most likely type of community resource to be used, not funded directly to serve people with disabilities, were family and friends (60.5%). The least likely type of community resource to be used by people with disabilities was civic organizations (9.7%). The type of community resource reported as most inadequate was also civic organizations (40.4% seen as inadequate). Social organizations were reported as inadequate by 25.9%, and fair by an additional 34.2%. Supports received from family and friends were rated as excellent by 38.2%, and 38.4% as good. Community support received through faith based organizations were rated by over 56% as either good (37.7%), or excellent (18.4%). Overall, 70% of the respondents reported the support they receive from their community as mostly, or somewhat supportive. Focus groups reported receiving community supports most often from *faith-based organizations, and family, friends, and neighbors.* Other supports were identified as *general support of community for persons with developmental disabilities, and other community groups.* It was reported by many that they experienced *good acceptance and support from the community, while at the same time a smaller number indicated a little or no acceptance.* Other attitude considerations expressed included the need for *community education and awareness about developmental disabilities, more acceptance of people with disabilities and the importance of getting to know people with disabilities and forming relationships with them.*

Safety and Quality Assurance Issues

Survey respondents were asked if they were aware any of incidents that affect the health, safety and quality of life of people with disabilities in their community. Of the 737 people surveyed, about 20% were aware of some physical abuse/neglect in their community; 16% were aware of sexual abuse; 21% were aware of some type of financial abuse; and 24% were aware of a human or legal rights violation. Respondents were also asked to share their perception about how the above types of incidents had been handled. Of those responding, the perception of about two thirds was that safety incidents were not handled well, or at all. Because the handling of these types of incidents often requires a degree of discretion, it is important to recognize that respondents perceptions of how these incidents are handled may not necessarily reflect what actually occurred to address them.

Almost 60% saw people with disabilities as being *mostly safe* or *very safe* in their community. Focus group participants discussed ways people with disabilities have been included in community life. The most common theme was through the *support and involvement of community organizations and businesses*. Also sited was the *general acceptance of people with developmental disabilities in the community*. Other ways they have been included is through the *support from faith based organizations that support persons with developmental disabilities in the community*. Respondents also reported that *families and friends advocate for persons with developmental disabilities to be included in the community*. Respondents were asked to identify ways people with disabilities are excluded from community life. *Attitude and lack of understanding of persons with disabilities* was sited most often as the reason for why they excluded from community life. Another way sited was that *individuals are excluded from community activities due to distance, transportation and other accessibility issues*. Respondents were asked to discuss how they were included in planning processes that affect their lives. Many felt that they had been involved planning processes affecting their lives. They also expressed that family/friends support persons to participate in the planning process, and that agency staff, teachers, and school counselors assisted as well.

Satisfaction with Services:

Service coordination was seen as good (40.3%) or excellent (29.8%) by over 70% of the respondents. The quality of provider services/supports was rated as good (40.8%) or excellent (24.1%), by almost 65% of the respondents.